

IFAASA

INFERTILITY SUPPORT

I am infertile - what now?

A Patient Advocacy Group's Role
in Patient Care.



An Educated Patient
is an Empowered Patient

#ourpurpose

IFAASA
ADVOCATE • INFORM • EMPOWER

www.ifaasa.co.za



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**INFERTILITY AWARENESS
ASSOCIATION
OF SOUTH AFRICA**

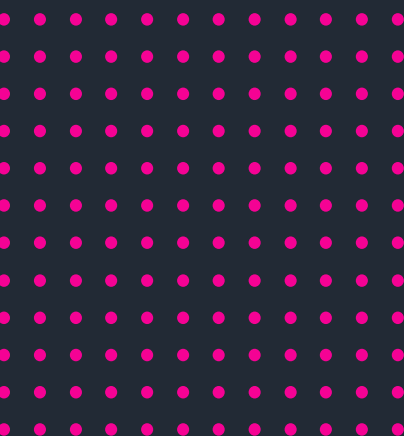
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Saskia Williams
Founding Director and CEO

How it feels to be infertile

Let us just remind ourselves...

- You sit in limbo, sometimes for years, watching your friends live their lives, as if through a window.
- You don't want to change your job, because you would like to enjoy the maternity benefits. So you don't move up the career ladder.
- You don't buy a house, or upsize your existing one because you need to keep the money for your treatment cycles.
- You don't treat yourselves to holidays, like your friends do. Each holiday could be a potential IVF Cycle.
- You stop going to celebrations where there will be pregnant ladies, small kids, or the chance of probing questions.
- Special days for others, like Mother's Day and Father's Day, become very difficult to navigate.
- You stop living a life full of colour, everything revolves around trying to get pregnant.
- Even when you do realise your dream and have a child, you are forever changed by the trauma and remain behind your friends in terms of life milestones.
- You are that older parent you never wanted to be, which is always a reminder of your journey. You can never escape it.



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infertility

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n.

Absent or diminished fertility.

The persistent inability to achieve conception
& produce an offspring.

Patient Advocacy in 2013 vs 2024

The patient advocacy landscape has changed exponentially in the past decade.

In 2013:

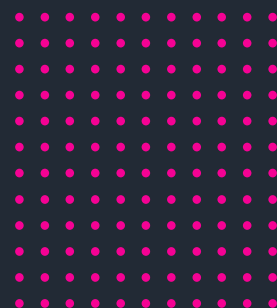
- Patients were desperate for information on their diagnosis.
- They felt alone.
- Their online support group profiles were anonymous, because they were ashamed of being infertile due to the stigma surrounding it.
- They didn't necessarily know that infertility is actually classed as a disease.
- They didn't realise that it affected 1 in 6 couples.
- Women blamed themselves.
- The in-person information sessions we held were sold out days in advance.
- There were no Webinars or Instagram Lives.
- Radio and TV interviews were often requested.



Patient Advocacy in 2013 vs 2024

In 2024:

- Fertility on social media has boomed.
- Businesses have been formed around getting information out to the public.
- There is actually too much information out there. Some of which is very misleading without any context.
- Patients are confused and some presume that, doing exactly what the TikTok star did, will also work for them. Sometimes insisting that their Doctors try it on them.
- Online support groups are on Facebook or Whats App and are no longer anonymous.
- Information sessions are mostly done online or via IG Live.
- In-person events aren't as well attended as they were, even a few years ago, because there is so much information available right in front of them with no need to leave home.
- Media doesn't seem as interested in covering infertility anymore, it's seen as old news and when they do, they get their info from google.



Patient Advocacy in 2013 vs 2024

What does all this mean?

- This means that the way we help and support patients needs to also change.
- We have a responsibility to the public now more than ever, to ensure that the information we put out to them is true and up to date, including information on realistic outcomes to manage their expectations.
- This includes videos on why something that works for someone else, may not work for them – back to basics.
- We also need to consistently encourage them to seek mental health help, to manage the additional stress that infertility and life in 2024 is hard to navigate anyway.
- Our most important mission remains to ensure treatment to become more accessible for everyone and not just those who either have a very comprehensive or executive plan, or who live within Steve Biko, Tygerberg or Groote Schuur's areas.
- This also means that we need to reach them where they are – TikTok



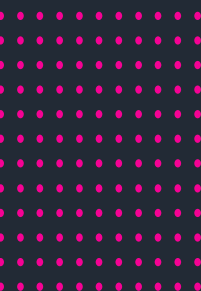
Patient Advocacy in 2013 vs 2024

How do we educate and empower Patients?

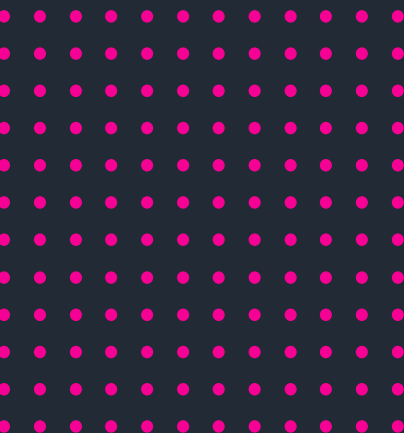
- We are on Facebook, Instagram, YouTube, LinkedIn and yes, even TikTok!
- Targeted and themed Social Media Campaigns - 13,332 followers

Campaign examples:

- Reproductive Health Month – Feb – campaigning for early detection of infertility
- Endometriosis Awareness Month – March
- National Fertility Awareness Week - July
- PCOS Awareness Month – September
- We hold Webinars featuring local and international Specialists, as well as ones around the world.
- We hold in-person information sessions and Baby Loss Support Groups.
- We run the Your Journey to Parenthood Show: 27 – 28th July at Kyalami International Convention Centre.
- We are currently running a Perinatal Bereavement Course for Healthcare Workers in Maternity and NNICU wards around the country, helping them to develop the skills to guide parents onto the path of healthy bereavement but, Michelle will tell you more about that.



The importance of a Tribe



IF A A S A

hope

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n.

A feeling of expectation and desire
for a particular thing to happen.



South Africa's
Number One
Patient Advocacy
Group

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